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BARRIERS TO SUCCESSFUL CERVICAL CANCER SCREENING IN RURAL KWAZULU-NATAL, CATO MANOR, AND CAPE TOWN

Keywords: Cervical Cancer, Public Health, Prevention

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ABSTRACT

In 2000, the South African Department of Health produced a nationwide policy intended to combat the growing crisis of cervical cancer. Nearly fifteen years later, however, the disease remains a significant cause of death among certain female populations, especially those who are rural, poor, and HIV-positive. It is undeniable that challenges of access, awareness, resource demand, and stigmatization stand in the way of complete policy enactment.

In this study, I explore in detail the barriers that prevent successful implementation of the policy. My research combines interviews with a variety of individuals and participant observation at the Cancer Association of South Africa. Interviews conducted among women piece together perceptions of the disease and the factors that successfully motivate (or in many cases, fail to motivate) the choice to be screened. Additionally, experts, medical professionals, and academics are consulted to explore the combination of socioeconomic, physical, emotional, and cultural factors behind such decisions on the part of both women and professionals. Ultimately, this investigation reveals the weaknesses in the nationwide policy of 2000, and offers a glimpse of how it may better become a reality in the future.

INTRODUCTION

In the global north, cervical cancer is almost entirely preventable, thanks to screening technologies and a relatively new HPV vaccine. Yet much of the global south remains extremely vulnerable to the disease. Particularly in South Africa, “cervical cancer is the most commonly

diagnosed form of cancer" (Ramikisson et. al, 2010, p.39). The disease, which has been described as one of the "economically disadvantaged", is most common among women who are rural, poor, and of low socio-economic status (Sibiya, 2012, p.40). At times, the most vulnerable populations may also be identifiable by race: "black women are most at risk of getting cervical cancer compared to white and coloured women in South Africa" (Sibiya, 2012, p.39). The issue becomes even more relevant in a nation plagued with high rates of HIV, as positive women are almost five times more likely" to develop cervical cancer and to contract it "at a younger age and a greater severity" (Ramkisson et. al, 2010, p.39) (Sibiya, 2012, p.44).

Given these surprising and disturbing statistics, health organizations and policy-makers have recognized the need for action. Yet, despite the establishment of a national cervical cancer screening policy nearly 15 years ago, the disease remains a significant threat to many women in South Africa.

This study aims to investigate how screening has been improved in recent years, and how a variety of barriers continue to challenge the success of the nationwide policy. Interviews of women and experts, participant observation, and background reading are used to examine these topics in detail. The focus is specifically on the population most vulnerable to the disease in South Africa: black women of low socio-economic status. By consulting women of this demographic, and experts who work specifically with them, the study aims to understand a crucial question: why does cervical cancer, a nearly preventable disease, remain so prevalent among certain South African populations? Additionally, two issues are examined that are especially important when considering the context of cervical cancer in South Africa: screening for HIV positive women, and the potential of a preventative HPV vaccine newly available to young girls. Finally, the study highlights points of success and suggestions for the future in an

effort to understand ways in which the policy provisions can more effectively reach those most in need.

Part One: Disease Background & Context

I. Background & Risk Factors

Cervical cancer is a slow-developing disease that originates in the lower, narrow end of the uterus (Fact, 2013, p.1). It begins when normal cells lining the cervix transform to become abnormal, pre-cancerous cells called dysplasia. These cells are 100% treatable when detected, but may develop into cancer if left untreated (American, 2014).

There are many potential risk factors for cervical cancer, but the most prominent known cause, responsible for "about 70%" of cases, is infection with the human papilloma virus (HPV) (Green, 2014, p.1). HPV can be spread through "skin-to-skin contact, body fluids, and sexual intercourse" (Fact, 2013, p.2). It is a very common sexually transmitted disease that is highly infectious. In fact, "most sexually active people will get HPV at some time in their lives", but often will never know because their body is able to fight it off (Botha, 2009, p.444). In some cases, however, the infection may persist, eventually causing cancer (American, 2014). Two strains in particular, HPV 16 and 18, are precursors for cervical cancer (Fact, 2013, p.2).

Being as HPV is primarily transmitted through sexual activity, associated risk factors for cervical cancer include "early marriage, polygamous marriages, and high parity" (Anorlu, 2008, p. 42). Polygamy alone is "reported to increase the risk of cervical cancer two-fold" (Anorlu, 2008, p.42). Early age at sexual debut, number of sexual partners, young pregnancy, smoking, and family history also factor into risk level. In addition, a weakened immune system interferes

with the body's ability to fight off HPV infections and early cancers. This is especially problematic for women with HIV, who have HPV infection rates that are "ten times greater than those among HIV-negative women" (Ramkisson et. al, 2010, p.39).

Unique to other cancers, cervical cancer often develops for "10-20 years" before becoming invasive (Department, 2000, p.2). Therefore, it is most common in middle-aged women: "87% of cases occur in women over 35 years of age" (Sibiya, 2012, p. 39). The slow-growing nature of cervical cancer allows for early treatment, as "early changes can be picked up long before a proper cancer will ever develop" (Szarewski, 1994, p.10). However, it can also render symptoms invisible until the disease is advanced. Though symptoms are seldom detectable in early phases, late stage cervical cancer is associated with abnormal vaginal bleeding or discharge, pelvic and back pain, weight loss, and painful urination (Fact, 2013, p.5).

II. Prevention & Treatment

Primary prevention of cervical cancer is practiced mostly by reducing the risk of HPV infection through avoidance of risky sexual behavior and "measures like education about safe sexual practices" (Botha, 2009, p.444). However, another primary prevention strategy has recently been gaining traction. Two HPV vaccines that protect against cancer-causing strains of HPV are approved for use among females aged 9-25. According to Ramikisson et. al, "vaccination is the only realistic strategy for prevention" (2010, p.39). "Both vaccines have been studied in large populations and have been found to be safe, effective and well-tolerated", but as of yet their use remains primarily restricted to developed nations (Botha, 2009, p.445). However, a recent push by the South African government to vaccinate schoolgirls is the first time the controversial method has been given substantial attention in Africa (Green, 2014, p.1).

Even with the presence of these methods, "screening for early diagnosis and treatment of pre-cancerous lesions" is crucial (Botha, 2009, p.445). There are several modes available, and much debate about which is best. The most common screening procedure is a Papanicolaou (Pap) smear, where cells from the surface of the cervix are collected and viewed in a laboratory on a stained microscope slide to detect abnormalities (Fact, 2013, p.6). This method is largely regarded as "one of the most cost effective ways to determine if a woman has cervical cancer" (Duckitt, 10 April 2014, pers comm). Indeed, the incidence of the disease "can be reduced by as much as 80% if the quality, coverage, and follow-up of screening are high" (Sankaranarayanana, 2001, p.955). Yet this may not always be possible, and disadvantages of Pap smears include the laboratory requirement and the follow-up visit needed to disseminate results. This may be avoided in low-resource settings with an alternative, once-in-a-lifetime screening method known as visual inspection with acetic acid, or VIA (Sankaranarayanana, 2001, p.955). This method "consists of naked eye visualization" of the cervix after diluted acetic acid is applied to highlight areas of concern (Sibiya, 2012, p. 45). The advantage of this procedure is that it requires "only low-technology equipment and the result is available immediately…treatment of abnormal lesions can be done during the same consultation", thus minimizing the difficulties of follow-up and resource procurement (Sibiya, 2012, p.45).

Another diagnostic tool that can be used in conjunction with Pap smears is the HPV test, which checks cervical cells to determine if cancer-causing types of HPV are present. Women with positive results, who may be more at risk of developing cervical cancer, are encouraged to go for annual Pap screenings, while those with negative tests may be candidates for the HPV vaccine as a preventative measure (Duckitt, 10 April 2014, pers comm). According to Professor Denny, a world-renowned cervical cancer expert, this molecular test is the best available method,

though “it is not very specific and tends to over-diagnose” (14 April 2014, pers comm). In addition, the HPV tests are more readily available at “private pathology laboratories in South Africa and are relatively expensive” (Botha, 2009, p.446).

With regards to secondary prevention methods, the one most frequently practiced in South Africa is colposcopy, which utilizes a magnifying instrument to check the vagina and cervix for abnormalities. This is often done following a Pap smear with abnormal results (Duckitt, 10 April 2014, pers comm).

The final step, tertiary prevention, involves treating detected abnormalities. Treatment method depends on the stage of the cancer, the preferences of the woman, and the nature of the tumor (Fact, 2013, p.6). Many abnormal results may simply be low-grade lesions that are left untreated. However, patients with such lesions are recommended to follow-up frequently, as progression to high grade, riskier lesions is possible (Denny, 14 April 2014, pers comm).

Unfortunately, cervical cancer treatments are usually “very expensive” and often not widely available or realistic in resource-poor settings in South Africa (Hill, 10 April 2014, pers comm). Therefore, much discussion surrounding solutions focuses on the importance of emphasizing primary and secondary prevention, as “screening services have been shown to be extremely cost-effective when compared with services that treat cases of invasive disease” (Hoffman et. al, 2002, p.573). While choosing a culturally and environmentally appropriate screening method is a large component of cervical cancer prevention, it is not nearly enough for long-term success. It is important to note that “a more fundamental and challenging issue is the organization of the programme in its totality” (Sankaranarayanana, 2001, p.959).

III. World Prevalence & South African Context

Throughout the world, cervical cancer is a telling marker of drastic inequalities in health, gender, and income. Indeed, "worldwide women of low socioeconomic status have a greater risk of cervical cancer" (Anorlu, 2008, p.43). It is the "leading cause of cancer death in disadvantaged populations" (Hoffman et. al, 2002, p. 573). Of annual deaths due to the disease, "80% occur in developing countries and this proportion is expected to increase to 90% by 2020" (Fiander, 2001, p.122). Africa alone has "nine-times the incidence of cervical cancer compared with the USA and 24-times the mortality" (Fiander, 2001, p.123). This may be due to the fact that "only 5% of women in developing countries undergo cervical cancer screening compared with 40-50% in the developed world" (Sibiya, 2012, p. 40).

One fact, however, that holds true across national boundaries, is the impact of screening measures on cervical cancer prevalence. Even "developing countries' screening programmes, conducted at a much lower intensity than those practiced in the West, can substantially reduce incidence from a preventable disease" (Hoffman et. al, 2002, p.576).

In South Africa, "cervical cancer is the second most common cause of cancer" among females, "with 1 in 41 women developing the disease in her lifetime" (Sibiya, 2012, p.39). However, it is also "the most deadly because it is often detected too late": over 50% of those who contract it annually die (Green, 2014, p.1).

The table shown below, provided by the 2005 National Cancer Registry, highlights the prevalence of cervical cancer among different populations in South Africa (Fact, 2013, p.2).

Group	**Number of Cases**	**Lifetime Risk**
All Females	4,851	1:39
Asian Females	66	1:92
Black Females	3,995	1:33

Coloured Females	398	1:44
White Females	392	1:81

It is important to recognize that cervical cancer is "the most common cancer in Black women" (Mosavel, 2009, p.116). According to a 2004 Department of Health report, black women are "most at risk of getting cervical cancer compared to white and coloured women" (Sibiya, 2012, p.39). Contrasts of disease rates across lines of income and race is also illustrated by the observation of one health provider working in the oncology unit of a government hospital primarily serving low-income women: "in the private sector, gynecological cancers are relatively rare, whereas here they make up 60% of the entire department" (Paris, 8 April 2014, pers comm).

In South Africa, cervical cancer is also especially prevalent amongst HIV-positive women, who frequently make up the largest proportion of patients at treatment centers (Paris, 8 April 2014, pers comm). A lack of effective screening programs among these women is particularly concerning because they are already disadvantaged by their heightened risk (Sibiya, 2012, p.44).

Too often, the statistics fail to reveal the increased incidence of cervical cancer among black, low-income, and HIV-positive women. The disproportionate burden of the disease on these populations in South Africa is indicative of the failure of the national policy to truly reach those who are most vulnerable.

Part Two: Cervical Cancer Screening National Policy

I. History and Current Policy

The alarming rates of cervical cancer in South Africa, and the fact that Pap smears have "significantly reduced the prevalence of the disease in countries where formal population-based screening has been implemented" have ultimately led to government recognition of the need for

action (Snyman, 2013, p.2). Yet, past attempts at combatting cervical cancer in South Africa have seen little success. In the 1970s, a highly criticized Department of Health policy "suggested that a Pap smear should be taken only if the cervix appeared abnormal", and in 1995 a similar policy in the Western Cape mandating regular Pap smears after age 30 failed for lack of education of both health personnel and women (Hoffman et. al, 2002, p.576). However, in 2000, the Department of Health "identified cervical cancer as a health priority" and announced a nationwide screening program (Sibiya, 2012, p.39). This policy states "every woman attending public sector health services is entitled to three free smears from the age of 30 years at intervals of 10 years" (Sibiya, 2012, p.39). This age range was selected because the slow-developing nature of cervical cancer "implies that a single smear performed within this period will diagnose the disease" (Department, 2000, p.3). Ultimately, the goal was to "screen 70% of women in the target age group within 10 years", and to "decrease cervical cancer incidence by 64%" (Sibiya, 2012, p.40). These goals were created with the reduction of "the excessive expenditure of scarce health funds currently spent on the treatment of invasive cancer of the cervix" in mind (Department, 2000, p.4). The policy also proposes that "the time lapse between screening and follow-up should be 1-4 weeks", with the responsibility of tracing patients and encouraging returns resting with the provider institution (Department, 2000, p.7). Finally, the policy makes note of the World Health Organization's recommendation that the number of smears provided per women per lifetime should be reduced "in favour of more women in the population having fewer smears" (Department, 2000, p.5). Though "in most developed countries women are advised to have their first smear test soon after becoming sexually active and subsequently once every 1-5 years", both WHO and South Africa's guidelines reflect more realistic parameters in resource-poor settings (Sankaranarayanana, 2001, p.955).

For HIV-positive women, policy differs slightly. It "includes a Pap smear on diagnosis or from age 20 and yearly or thrice-yearly thereafter" (Ramkisson et. al, 2010, p.39). In particular, "Western Cape policy states that HIV-positive women should be tested every 3 years if the initial screen is normal"(Botha, 2009, p.446). This guideline is especially relevant in a nation plagued with high rates of HIV. In recent years, with the availability of antiretroviral treatments allowing infected individuals to live longer, it also merits greater attention.

II. Evidence of Failed Implementation

Despite these promising guidelines, as of 2010 the policy had been "implemented in some areas but not throughout the country", and "no population-wide screening programme" exists currently in South Africa" (Botha et al., 2010, p.23). Across the nation, it is "estimated that the screening coverage, which is mainly done on an opportunistic basis, is as low as 13%" (Snyman, 2013, p.2). Professor Denny acknowledges that "opportunistic screening", or limiting testing to those who happen to be in a clinic for other health concerns, is partially responsible for such low coverage. It "is a much less efficient system", she says, "because you select out women who attend health clinics, as opposed to the general population" (14 April 2014, pers comm). For example, women are often routinely screened in antenatal clinics, but seldom after their pregnancies. One health promoter, formerly stationed in the rural Western Cape, says of the typical women she encountered; "maybe, she had a Pap smear 20 or 30 years earlier, when the last child was born" (Hill, 10 April 2014, pers comm). The experiences of many vulnerable women with regards to opportunistic screening are much in line with frustrations of health providers. Ella* says, "I have 4 kids and always had a Pap smear when I was at the antenatal clinic, but stopped after my last child. And that was 20 years ago" (8 April 2014, pers comm). Marie* had a similar experience: "I had a Pap smear when I was pregnant at 20 but not again

until I was 43" (8 April 2014, pers comm). As a result, women are not being screened nearly as often as the policy suggests, and "there are still far too many women who have never had a pap smear" (Briton, 9 April 2014, pers comm).

A lack of successful screening results in high mortality among certain populations of women, and most cases are "diagnosed at a late stage, with subsequent poor prognosis for long-term survival" (Botha, 2009, p.444). "Cervical cancer is still our biggest killer among women in *poor* communities", partially because unsuccessful policy implementation results in women delaying care until it is too late (Briton, 9 April 2014, pers comm). As a former health promoter and current manager of Eikehoff CANSA Care Home says, "they don't get Pap smears. It is only when they have abdominal pain or bloody discharge that they go in" (Hill, 10 April 2014, pers comm). Similarly, an oncologist at an urban public hospital insists "lack of hospital facilities isn't the problem unless you're in the extreme rural areas. Once they get to hospitals, things are okay, but they come with severe symptoms" (Paris, 8 April 2014, pers comm). In particular, he acknowledges that the worst cases he sees are often "far advanced tumors" from poor, rural women unexposed to any type of screening policy (Paris, 8 April 2014, pers comm). This concern was expressed after seeing a string of severely ill patients, including an elderly Xhosa-speaking woman who was in so much pain she could not even make it onto the hospital bed for an examination (Paris, 8 April 2014, pers comm). Cervical cancer patient Ruby* also offers evidence of this issue, revealing "I had a normal pap smear when I was 63 but in October I had heavy, heavy bleeding and went to the hospital. They removed my womb because there was cancer" (8 April 2014, pers comm).

Undeniably, there is a disconnect between the promises of the policy on paper and the reality of South Africa's vulnerable women. One health provider, who was forced to end her

cervical cancer screening clinic in a Cape Town townships due to lack of funding and government support, puts it bluntly; "cervical cancer has sort of fallen off everyone's radar. It's not 'sexy enough'" (Briton, 9 April 2014, pers comm).

The purpose of this study is to understand why these shortcomings occur, and why, exactly "effective implementation of formal population-based screening in this country is a long way off" (Snyman, 2013, p.3). While recent literature focuses on the technicalities of cervical cancer prevention, such as cheap alternatives for screening or the potential of new vaccines, little has explored the consequences of intersecting physical, socioeconomic, and cultural barriers. Yet it is crucial to understand these factors in order to gain a complete understanding of how the problem might best be addressed for sustainable future change. This study serves to fill in the gap by exploring the combination of factors that contribute to continued high rates of cervical cancer among low-income black women, despite the undeniable statistics and the existence of policy guidelines from over a decade ago.

METHODOLOGIES

Part One: Data Collection and Sampling Methods

This study combines participant observation and data collected from individual women and experts in an effort to identify both successes and failures with regards to policy implementation in a variety of settings.

Interviews were conducted with low-income black women from KwaZulu-Natal, Cato Manor, and Cape Town to investigate knowledge, experiences, and perceptions of cervical cancer, HPV, and Pap smears. Participants from Cato Manor, Nzinga, and Sandenezwe were selected based on the trusting relationships I was able to foster over time. In order to conduct research on such a sensitive and personal topic, I felt it was necessary to speak with women who

felt comfortable and open with me. Indeed, I found it was much easier to facilitate conversations and receive honest answers in return when women were at ease in my presence. All of these participants were Zulu-speaking black women from low-income areas. I chose this demographic because it has been identified as the population most vulnerable to cervical cancer in South Africa. I also consulted women of differing ages in the hopes that these perspectives would help to make the sample more representative. In Cape Town, I conducted four interviews with middle-aged, low-income, Xhosa-speaking cervical cancer patients at a CANSA Care Home, with the help of a translating nurse. These women were not captive informants, but rather chose to share their stories with me in a public space on their own time. Their status as patients experiencing the harsh reality of cervical cancer in South Africa brought a new perspective to my research, as did their differing geographic and cultural backgrounds. Names of all female participants have been changed (as indicated by asterisks) to protect privacy.

The study is further developed through interviews with experts, including academics, medical providers, and employees of NGOs who work with the issue of cervical cancer prevention on a daily basis. Depending on each expert's role, questions were structured appropriately to inquire about the challenges to implementing policy, the ways in which difficulties are overcome, and the experiences they have had with promoting screening. This information served to enrich data from human subjects and offer a comparison with which to pinpoint discrepancies and reasons why the policy has not seen success.

These types of participants were chosen through convenience, snowball, and selective sampling. Many health providers and associated staff members were chosen simply because of their presence in the settings I visited, their willingness to speak with me, and their level of experience and knowledge on the subject.

Additional experts and academics were chosen through snowball sampling and outside research. Through reading literature on cervical cancer in South Africa, and researching related NGOs, I was able to initiate communication with several individuals, including Professors Firnhaber, Briton, and Denny. I was also connected with others, including a social worker and a government hospital oncologist, through my advisor and mentor at CANSA. I chose to speak with these participants based on their extensive experience and passion for cervical cancer screening in South Africa. I also wanted to speak with knowledgeable individuals who could provide unique perspectives on the status of the issue in HIV clinics, government hospitals, townships, treatment centers, and rural areas.

Finally, a period of participant observation was completed at a Cape Town CANSA clinic, a NGO that offers screening and treatment for cervical cancer. Participation did not involve interviewing patients in the space, but rather volunteering and experiencing the issue through a more intimate lens. The three weeks spent in this setting allowed for the development of stronger relationships with staff and a daily glimpse at the challenges of their work, their personal solutions, and their ideas on the best ways to move forward. This stage complements the interviews and prior research completed. The opportunity to further develop my research in an observational study, rather than through one-time formal meetings alone, was quite valuable.

After the completion of this stage, data was supplemented by information I selectively gathered from secondary literature reviews. These reviews served to provide a foundational knowledge of the issues at hand and fill in the gaps that became apparent throughout my primary research. Finally, data was compiled in an effort to recommend ways in which the nationwide screening policy can more effectively address the issue in order to target South Africa's most vulnerable women.

Part Two: The Cancer Association of South Africa

I. Brief History and Current Work

Over eighty years ago, the first National Cancer Conference convened to establish what would become the internationally respected organization that is CANSA today. The organization continued to grow over the next decades, utilizing the hands of nurses, social workers, religious leaders, and volunteers to expand on its mission. By the 1980s, the National Cancer Association had become involved in international movements, hosting world conferences and collaborating on various research projects. In 1992, the name was changed to the Cancer Association of South Africa (CANSA) and a new corporate identity developed (Cancer, 2012, p.53).

Today, CANSA continues to expand on the work that was started over eight decades ago. The mission statement reads "CANSA's purpose is to lead the fight against cancer in South Africa by offering a unique, integrated service to the public which involves holistic cancer care and support to all people affected by cancer." (Cancer, 2010). This goal is supported by a large and comprehensive network that includes 50 nationwide offices, 14,000 volunteers, and 380 staff members (Cancer, 2012, p.53). Efforts are mostly funded by the Department of Health, private donations, and fundraising event revenues, and the work of CANSA is carried out through a "three-tiered service" composed of research, education, and support (Duckitt, 8 April 2014, pers comm).

II. Stance on Cervical Cancer

These approaches are utilized in many ways to combat cervical cancer. CANSA implements a vast number of programmes, mainly aimed at "making the public aware of the importance of early detection" (Position, 2013, p.1). In addition, CANSA publicly supports a variety of preventative measures, including the use of contraception, the postponement of sexual intercourse, the management of STIs, and decreasing parity (Position, 2013, p.3). With regard to Pap smears, CANSA's guidelines match those of the national policy, recommended by the World Health Organization and the Department of Health. However, while WHO proposes reducing the number of Pap smears per woman in an effort to reach a wider population, CANSA's position does not directly state that reduction of number of lifetime smears is the best approach, instead emphasizing the importance of reaching the greatest number of women possible (Position, 2013, p.5). At CANSA's screening clinics, approximately 20,000 Pap smears are performed annually, with the hopes that screening measures will be made accessible to all women (Position, 2013, p.1). CANSA especially highlights the necessity of taking a non-discriminatory approach and treating all women equally, most notably those afflicted with HIV/AIDS (Position, 2013, p.7)

Finally, CANSA supports many additional measures to improve cervical cancer screening. This includes training health professionals on the importance of Pap smears and cytology, improving education of communities on the HPV vaccine, and implementing effective record-keeping, follow-up, and referral services (Position, 2013, p.7). When performed in conjunction with the national policy, the hope is that these measures will successfully reach South African women most vulnerable to the disease.

III. The Mowbray Clinic

The Mowbray CANSA centre is one of many nationwide clinics offering prevention and treatment services for cancer. The site consists of nine staff members, including community mobilisers, fundraisers, volunteers, and Sister Duckitt, the clinic manager. The Southern Business Unit management branch, which presides over all southern clinics, is housed in the same building and includes a small staff of managers, human resource and finance departments, and a transportation team (Arnold, 9 April 2014, pers comm). In addition to the clinic, the Mowbray site also includes a unique feature of CANSA: a recently opened Science and Resource Centre that "houses the national Toll-Free Information Service, as well as all CANSA's science-driven projects and events" (Cancer, 2010). It is also a space not so dissimilar to a library, with resources and seminar rooms available to the public.

The facility, located just a few kilometers from Groote Schuur Hospital, resembles more of a cozy, familiar home than a sterile clinical setting. Carpeted floors and comfortable armchairs compose the waiting room, which is bordered by an ancient staircase leading to administrative offices. To the rear of the building are several clinical offices, a wig room, and storage spaces. Wide windows permit warm sunshine, city bustle, and an impressive view of Table Mountain to permeate. At the front desk, long-time receptionist Faieza greets all patients with a warm and knowing smile. The same sense of comfortable familiarity pervades throughout the small staff, also unique in that many of them have been directly affected by cancer, as survivors, widows or grieving friends. As one staff member says, "if I wasn't working for this organization, I wouldn't have survived. It was my therapy" (Arnold, 9 April 2014, pers comm). This personal connection to cancer not only serves as a means of support for staff, but also allows the entire process of prevention and screening to become "more personalized" (Duckitt, 4 April 2014, pers comm).

Despite the ideal setting and compassionate staff, the Mowbray clinic sees a fair share of downtime on-site. Increasing awareness and encouraging attendance is one significant challenge faced by the organization. Part of this may be due to the types of services the clinic offers. CANSA provides "in-between" Pap smears: the ones that come at shorter intervals than the recommended ten years. As a result, the smears require a fee of two hundred rand. This acts as a deterrent to many low-income women. At the Mowbray clinic, the most common patients are "women who cannot afford the private clinics or have no health insurance but can afford to pay the small extra fee" (Duckitt, 2 April 2014, pers comm). Instead, many of the lowest income women are seen at CANSA's mobile clinics that periodically travel through the Western Cape providing education and government-subsidized Pap smears. Women with abnormal results are then referred to hospitals that offer secondary prevention services like colposcopy (Duckitt, 8 April 2014, pers comm). While CANSA refers patients and frequently liaises with public hospitals during all steps of the process, the focus is on primary services, and the mantra remains "prevention is better than cure" (Mahali, 7 April 2014, pers comm).

The Mowbray clinic also participates in community outreach events, where NGOs convene in public spaces to distribute informative pamphlets or services like Pap smears, HIV tests, and childhood immunizations. Motivating participants can often prove a challenge at such events, due to lack of marketing and awareness, but this is combatted by providing free refreshments, advertising in local newspapers, and extending services over several days (Duckitt, 2 April 2014, pers comm).

CANSA uses a set of staff called "navigators" for these occasions. Navigators are young people recruited from within townships to raise awareness about cancer. They are provided with a stipend and a two-week training period before being given assignments that range from

manning information tables to distributing pamphlets at taxi ranks. An all-male navigator team addresses prostate and testicular cancer, while an all-female team tackles breast and cervical cancer. The idea behind the navigators is that "people are more likely to listen to those in their own community"(Duckitt, 2 April 2014, pers comm). In addition, their awareness of their neighbors' habits and needs, and their proficiency in native languages makes information accessible that may otherwise be difficult to glean from a more formalized medical setting.

Two "Care Homes" are additional unique and defining features of CANSA Mowbray. These sites are reserved for patients unable to find or afford accommodation in the city during the course of their cancer treatments at major hospitals. As a result, "about 99% of the patients are indigent" (Duckitt, 8 April 2014, pers comm). Both homes are run by a staff of four that includes a house manager and a chef. During the day, patients are transported to and from the closest hospital to receive their treatments. The homes also provide them with free, nutritious meals, support groups facilitated by CANSA employees, and a comfortable living space (Engelbrecht, 8 April 2014, pers comm).

The first Care Home, located within Tygerberg hospital, accommodates 12 women and 8 men whose length of stay varies depending on need. Patients are referred by doctors at the hospital, and often initially placed on a waiting list: not surprisingly, beds are in high demand. Most of the patients are colored or black, low income, and from rural areas. According to house manager Mandy Engelbrecht, they are very grateful to be receiving such care at no cost. Patients often leave thank-you cards or come back to visit after leaving (8 April 2014, pers comm). Undeniably, "there is a sense of family at the CANSA Care Home because they're all in the same boat fighting cancer…it's a home away from home where they don't have to worry about any bills or problems" (Engelbrecht, 8 April 2014, pers comm).

The second Care Home, Eikehoff, has a similar supportive and compassionate feel, despite the fact that it is located in a donated neighborhood house and has an entirely different staff. Like the Tygerberg Home, "most of the patients are lower income from rural areas. Even those seeing private doctors are usually on medical aid. They are asked to give a donation but most of the time they cannot afford it" (Hill, 10 April 2014, pers comm). Patients here experience more of a home-style setting with a lounge, dining room, outdoor courtyard, and furnished bedrooms. House manager Michelle Hill notes that being in a safe environment with the opportunity to talk amongst themselves is therapeutic for the patients: "when they come, they don't want to talk about their disease. At home with their families, they never talk about it, but here they are all going through the same pain and treatments, and they can talk with each other" (10 April 2014, pers comm). In this way, the homes offer care that is innovative and rare when compared with more conventional set-ups. They provide a comfortable setting that is valuable for patients who are far from home, suffering, and unaccustomed to healthcare so nurturing and complete.

Despite the undeniable challenges and setbacks, this aura of camaraderie, support, and comfort, pervades many aspects of CANSA Mowbray. The close-knit staff works tirelessly to provide patients with everything they need, from three warm meals at the Care Homes, to an understanding ear at support groups, to an empathetic explanation for women learning about reproductive cancers for the first time. Though they face struggles of disorganization and funding common to any NGO, I was also able to observe countless examples of high-quality care and dedication to cervical cancer prevention with CANSA in many different settings.

LITERATURE REVIEW

A variety of research has been conducted to shed light on the challenges of cervical cancer screening in developing countries. Such research has been necessary given the continued high prevalence of a preventable disease and the fact that it is common for women to "seek help only when their disease is far advanced…rendering cure or control nearly impossible" (Sibiya, 2012, p.39).

One factor consistently cited as a significant barrier is the lack of access to care. Only "23% of South African women have consistent and regular access to pelvic examinations and 51-60% of women have never had a pelvic examination" (Ramikisson et al, 2010, p.39). Further complicating the process is the fact that many screening methods require subsequent visits, and follow-up rates are often quite low. While women may be able to access a clinic one time, "tests that require additional recalls and revisits for diagnostic evaluation and treatment may pose added logistic difficulties and these may emerge as another barrier for participation" (Sankaranarayanana, 2001, p.959). Therefore, even if they are diagnosed with infection, they may "receive incomplete treatment, because they cannot access (financially or geographically) good health care" (Anorlu, 2008, p.43).

Lack of access goes hand-in-hand with low economic status, as women are frequently "not completing treatment due to barriers imposed by poverty" (Anorlu, 2008, p.42). Commonly, cervical cancer is referred to as "'a disease of the economically disadvantaged' because even in developed countries such as the United States, cervical cancer mostly affects women of low socioeconomic status, rural and poor women" (Sibiya, 2012, p.40). It is also suggested that those who need attention most are not accessing the available care: " women who use these services are generally young, and smears are thus being taken from a relatively low risk group", while older women, especially those in rural areas, are not reached (Anorlu, 2008, p.44).

The high cost and resource investment associated with preventative measures is another barrier to successful prevention. Unfortunately, "substantial costs are involved in providing the infrastructure, manpower, follow up and surveillance for cervical cancer screening programmes" (Sibiya, 2012, p.40). Many low-income countries "have neither the resources nor the capacity for their health services to organize and sustain any kind of screening programme" (Sankaranarayanana, 2001, p.954). Some go so far as to say that "screening using cervical cytology is not feasible in most developing countries due to the financial, technical and infrastructure investments" (Fiander, 2011, p.130). Resource shortages may be especially problematic in places like public hospitals, accessed by the most vulnerable populations. For example, the "capacity to read the cervical smears at public sector laboratory is limited" and often includes at least a month-long wait between test and result (Sibiya, 2012, p.42). Previous literature also cites a properly functioning and organized administrative system as a crucial resource that is lacking. One study examining the effects of resource shortages on screening reports; "referral hospital feedback was poor, record keeping was inadequate, and rural clinics lacked resources" (Sibiya, 2012, p.41). In addition, "poorly functioning administrative and transportation systems", and "lack of effective liaison with referral centres for diagnosis and treatment" may deter women from following-up, if they choose to seek treatment at all (Sibiya, 2012, p.43).

Even if women do have access to screening and resources, limited knowledge of Pap smears and cervical cancer may prevent action. Studies have found that "knowledge about cervical cancer and Pap screening is extremely low in developing countries"(Mosavel, 2009, p.116). Particularly in South Africa, many women are "minimally literate and have very little knowledge about cervical cancer and the tests to screen for it" (Snyman, 2013, p.2). Mosavel's

research, which reports that many rural South African women "felt that screening is unnecessary when a woman does not feel ill", exemplifies this point (2009, p.117). Though women may be aware of the disease, misconceptions are known to contribute to poor prevention habits. However, it is suggested that lack of knowledge may not be restricted to patients: often "health care workers who are supposed to be better informed do not have good knowledge of the disease either" (Anorlu, 2008, p.43). This lack of awareness may prevent women from making fully educated choices about their reproductive health. It may also be true that "better knowledge may lead to increased acceptance of screening requirements by women" (Botha, 2010, p.24).

Acceptance of screening may currently be challenged by shame, fear, and stigmatization. In his research, Dr. Botha has found that the "diagnosis of HPV infection may have a negative psychological impact on the woman" (2010, p.25). Women may also be "frightened of having a Pap smear because they don't know what it will involve, or even worse, a friend has had a bad experience" (Szarewski, 1994, p.13). Besides fear, the "embarrassment of the procedures involved and the association of cervical cancer with sexual behavior" are cited as reasons women may choose not to be screened (Szarewski, 1994, p.174).

A plethora of other barriers have been identified as possible factors in the poor success of cervical cancer screening programmes in both the developing world and South Africa specifically. Often, these barriers are deeply intertwined and viewed as a set of interacting influences, rather than as individual components. This study looks at these barriers, focusing specifically on those that are socioeconomically and culturally unique to the South African females and experts consulted.

FINDINGS & ANALYSIS

Part One: Barriers to Successful Policy Implementation

I. Lack of Access & Failure to Follow-up

Geographic and financial barriers to accessing both initial screenings and crucial follow-up appointments appear to be a significant challenge to the success of nationwide policy implementation. For rural, low-income women this is particularly problematic because "they are further away from tertiary institutions. They only come to bigger hospitals when referred and usually that's when they have progressive stages of cancer" (Duckitt, 8 April 2014, pers comm). Daily transportation services to major public hospitals are available from many rural areas in the Western Cape, yet as oncologist Dr. Paris points out, "ambulances and busses will bring them down, but this is difficult for the patients receiving 6 weeks of treatment" (8 April 2014, pers comm). In particular, "the ones that really have it bad are those that aren't quite rural but are too far to travel comfortably" (Paris, 8 April 2014, pers comm). Professor Briton agrees, saying that in addition to the time dedication and geographical constraints, the main challenge is simply that "they've got no money" (9 April 2014, pers comm).

Even if patients are able to make it to urban hospitals after being referred from a local clinic, the visit is frequently unproductive. When rural patients arrive early on the once-daily bus, they are given a nametag that reads "country" to indicate to the nursing sisters that they must be seen before four PM, when the return bus leaves. Such women, equipped with overnight bags in anticipation of not being seen, are frequently turned away come afternoon. Nursing sisters will often supply a small snack along with the bad news, as patients usually wait from dawn onwards without eating (Duckitt, 10 April 2014, pers comm). The fact that many rural patients are unable to afford the transport and costs of overnight city accommodations undeniably acts as a deterrent to proper access of prevention services. Though some health providers say access and transport "really isn't their problem to solve", others try their best to be

sensitive of accessibility challenges for patients (Paris, 8 April 2014, pers comm). The weekly Groote Schuur colposcopy clinic is appointment-based, but no one is ever turned away. Women often show up after their scheduled date due to accessibility difficulties, but, according to one doctor, "it is too precious a moment to turn them away"(Denny, 14 April 2014, pers comm).

Similar barriers to access prevent women from following up to receive test results or treatments for abnormal outcomes. Failure to follow-up is one of the most frequently cited challenges. Often, access to the actual Pap smears is "okay, but then when you have abnormal results you can get a long period of waiting" that deters many women from returning, due to constraints of environment and finance (Firnhaber, 17 March 2014, pers comm). Surprisingly, young women in particular may be more prone to missing follow-ups. According to Professor Briton who managed a township cervical cancer screening project, "we had to push the younger women more to follow-up because they're so mobile" (9 April 2014, pers comm). The problem persists perhaps more prominently in rural areas, where "it takes weeks or even months to get Pap smear results back from the lab"(Briton, 9 April 2014, pers comm).

II. Resource Shortages

Lack of access and failure to follow-up are exacerbated by the shortage of resources needed for successful prevention programs. Many health providers lament this challenge, and voice similar concerns that "with the limited resources, we can only do so much" (Mahali, 7 April 2014, pers comm). The "big challenges are finding a bed, finding transport-raw logistical challenges" (Paris, 8 April 2014, pers comm). In community clinics and public hospitals, these difficulties are frequently observable. At an outreach event based in a township community clinic, one frazzled nursing sister was tasked with providing Pap smears to a crowd of dozens of waiting women because only one bed was available, though several other nursing sisters on-site

were capable of providing screenings as well. At a government hospital clinic, similar challenges arose: in just a few hours, the oncologist on staff referred three very ill females back to the waiting room, in the hopes that a hospital bed would open up before nightfall.

In many rural areas, the lack of resources is dire. One health provider acknowledges that "still, in this day and age, running a screen-and-treat clinic in rural areas is very difficult" because the procedures require resources that may not be feasible to transport and maintain in rural clinics (Briton, 9 April 2014, pers comm). In addition, many of the procedures require that "nurses must have some kind of IT knowledge", though the reality is that few do (Briton, 9 April 2014, pers comm). Screening services are not the only things that require precious resources. Adequate prevention involves going beyond screening alone: "you need basic support as well-nutrition in addition to Pap smears." (Paris, 8 April 2014, pers comm). Successful prevention also involves effective follow-up. To achieve this, managers of a Western Cape township screening project practiced careful tracing and paid large sums to track people down and transport them. "It costs a lot of money to keep the follow-up rate high", says one staffer, acknowledging the difficulty of re-creating this success in a real-world scenario without the funds and the dedication of a university medical team (Briton, 9 April 2014, pers comm).

A lack of resources in the form of capable manpower is also a significant burden. "Having enough people to do the Pap smears on a daily basis", not to mention "people who care about doing this", is a frustration of many health providers (Firnhaber, 17 March 2014, pers comm). In addition, NGOs and public health sites face the problem of quick staff turnover. At one organization providing screenings to HIV-positive women, a provider reports "problems with lots of staff resignation", which becomes complicated by the fact that "it takes a long time to train people" (Firnhaber, 17 March 2014, pers comm). Similarly, CANSA struggles with

frequent staff turnover and finding both the manpower and funds to fully support its work. One staffer puts it best, saying, "there is always a need. With an NGO, sometimes, it can be hard to find the funding" (Hill, 10 April 2014, pers comm).

The problem of understaffing specifically manifests itself through long waiting times. At major public hospitals, it is common for patients to line up outside the outpatient clinic at 4 AM and wait the entire day to be seen (Duckitt, 10 April 2014, pers comm). Similarly, waiting lists for follow-up appointments are devastatingly long: I observed one provider examine a patient who had abnormal results nearly seven months earlier. The "general disorganization" of public health centers is doubtless both a factor in and a consequence of the long waiting times, understaffing and underfunding that plague them. The lack of truly stable administration and a sound South African political institution dedicated to public health poses a daunting challenge to improving cervical cancer screening.

III. Inadequate Knowledge & Awareness

A lack of proper knowledge and awareness about the realities of cervical cancer is another barrier that continuously arises as a challenge to successful screening. Health providers agree that, "there is very little awareness regarding cervical cancer screening and the importance of Pap smears" (Briton, 9 April 2014, pers comm).

Though females may know about the existence of the disease, they often do not know the details, and "many South African women construct cervical cancer in nonmedical terms and rarely use the term *cervix"* (Mosavel, 2009, p.125). Frequently, the most vulnerable women of low socio-economic status "don't really understand the biological components of the body. Often they refer to it as cancer of the womb" (Hill, 10 April 2014, pers comm). Ruby*, a cervical cancer patient, acknowledges that "I didn't really know much about cervical cancer before I had

it" (8 April 2014, pers comm). This is especially true among particular populations: "urban women know about the screenings, but not as much the rural women"(Duckitt, 8 April 2014, pers comm).

Much of the knowledge that women do have of the disease comes from personal experience or word-of-mouth. I spoke with Ndu*, a 58 year-old Zulu resident of an urban township in KwaZulu-Natal who recalled watching her own mother die of "cancer of the womb" when she was just fourteen years old. She says that her mother lost her hair and large clots of blood, recalling, "she had womb pains and was bleeding so much from a tumor" (Ndu*, 9 March 2014, pers comm). Nandi*, another 54 year-old Zulu-speaking resident of rural KwaZulu-Natal had a Pap smear at the local clinic at age forty "to check for cancer" (7 March 2014, pers comm). When asked about cervical cancer specifically, she reported gravely, "it's the disease where you keep bleeding like you are menstruating" (Nandi*, 7 March 2014, pers comm).

Part of the problem is the whirlwind of misconceptions and misinformation that comes with a disease so closely related to issues of a private and sexual manner. Because it is customary to get Pap smears after or during pregnancy "there is the misconception that the smears are used to clean the womb (Hill, 10 April 2014, pers comm). In addition, because cervical cancer is caused by HPV, a sexually transmitted infection, many women believe that they are not at risk for the disease unless they are sexually active. One health promoter observes, "the perception is that if I had my baby 25 years ago and I haven't been sexually active since, I don't need one" (Hill, 10 April 2014, pers comm). Similarly, "with the older ladies, since they haven't been sexually active, they feel there isn't a need to get one" (Hill, 10 April 2014, pers comm). This is complicated by the slow-growing, symptomless nature of early cervical cancer. "How do you tell a lady of 60 that she has a sexually transmitted infection?" wonders one health promoter, "the

fact that there's no real signs and it can stay in your body for a long time makes it difficult to explain to women." (Hill, 10 April 2014, pers comm). Though much more rare, the same misconception occurs among young women. "I knew I should go for Pap smears some time", says cervical cancer patient Mary* "But I thought it wasn't necessary to go because I was only 17 and was not sexually active" (8 April 2014, pers comm). Due to the emphasis placed on females in discussion of the disease, women also may not realize that they can still contract HPV in a committed relationship with a longtime partner. It is important to recognize that "although a woman may have been faithful, her partner may place her at risk" (Szarewski, 1994, p.175).

Others have misconceptions surrounding the nature of cancer, as it is a topic oft avoided in many populations. One young man in a rural region of KwaZulu-Natal reports confidently that, "cancer is a disease of white people. Black people don't really get it. " (Bua*, 19 February, 2014, pers comm). Others are quick to associate cancer with death. Ndu* insists that, "HIV is better because you can take a treatment. But cancer is very bad." (9 March 2014, pers comm). The same fatalistic attitude prevails in many poor black communities in the Western Cape, where "there is the stigma of cancer meaning death" (Gwebile, 17 April 2014, pers comm). A social worker who sees this outlook frequently among her newly diagnosed and fearful patients suggests, "we need more awareness because people don't know what is available for treatment out there" (Gwebile, 17 April 2014, pers comm).

Fragmented knowledge, misconceptions, and lack of awareness may at times be responsible for low rates of screening among vulnerable South African females. As one 22 year-old Zulu speaking resident of an urban township in KwaZulu-Natal says, " Not many people know about it, so even if they are sick they never know" (Thanda*, 5 February 2014). Lack of widespread awareness and adequate knowledge may also lead to women delaying screening in

favor of other activities. Sister Duckitt, a nurse at CANSA, observes that many women "have heard of cervical and breast cancer, but they put their needs behind the ones of their babies and their husbands" (Duckitt, 2 April 2014, pers comm). For many females, the reality is that "cancer is not at the top of their priority list. They are too preoccupied with other aspects of their life" (Paris, 8 April 2014, pers comm).

IV. Fear, Shame & Stigmatization

Inadequate knowledge about cervical cancer and screening methods in particular is often cause for fear and embarrassment that prevents women from taking action. "One common response I get when trying to convince women to get a smear is 'No, absolutely no way' or 'I'll think about it'", says one nursing sister (Briton, 9 April 2014, pers comm). Another nursing sister at a rural health clinic in KwaZulu-Natal says that getting women to agree to have a Pap smear can be a battle; "We have to ask and beg them. They don't like it. Especially the old ladies. They are embarrassed because they are scared to expose themselves to us" (Ama*, 10 March 2014, pers comm).

Sure enough, Lovia*, a 26 year old Zulu-speaking resident of an urban township in KwaZulu-Natal says, "I didn't have one because I was scared. I didn't want to have him look up inside of me…Even when I was pregnant and they told me I'd have to have one, I said 'No'"(13 February 2014, pers comm). Lovia* had never had a Pap smear before, and was not informed of what it was or the importance of getting one at this particular visit, which may have contributed to her fear and mistrust. Others, like Ndu*, have had a screening and still associate the procedure with some degree of fear. Of her experience, she says, "it is easy but a little painful and you're so frightened for the doctor to look at your private parts" (Ndu*, 9 March 2014, pers comm).

Nandi* recounts her experience with less fear, though she hypothesizes that this does deter many women; “most women are not getting them because they are afraid and they think it will hurt. But I had mine and it was not painful” (7 March 2014, pers comm).

Beyond preventing women from requesting screenings, fear and shame has been known to deter women from seeking help even when they notice a problem. “It used to be that women would have a problem, they wouldn’t report it, and then they would die because it just wasn’t discussed”, says Professor Olivia Briton of her past experiences with poor female patients in a Western Cape township (Briton, 9 April 2014, pers comm).

Anxiety also extends beyond the initial examination alone, and “fear of what the result might be” is often a greater source of worry and shame (Briton, 9 April 2014, pers comm). The same “connotation that it’s a sexually transmitted infection” that fuels misinformation and incomplete knowledge is at times responsible for inspiring stigmatization (Hill, 10 April 2014, pers comm). “Because HPV is sexually transmitted, many women feel embarrassed”, and are fearful of being diagnosed with something that is so stigmatized in South African society (Duckitt, 10 April 2014, pers comm). With the height of the HIV epidemic, HPV has become even more stigmatized, and “there is also potential for confusion with HIV in the mind of the patient” (Botha, 2010, p.25). For women who are HIV-positive, and thus more at risk for developing cervical cancer, the threat of being diagnosed with a second infection is understandably unappealing. It is common for these women to skip Pap smears even if referred for one because they “don’t want to stand in another line or be diagnosed with another disease”(Firnhaber, 17 March 2014, pers comm).

In addition, the lack of open discussion and understanding surrounding cervical cancer leads to a stigmatization of the disease that sparks shame among women who have it. “You don’t

really know if people have it", Ndu* says, "people get embarrassed to talk about it" (9 March 2014, pers comm). A social worker at Groote Schuur Hospital, observes that her patients' "biggest concerns are lack of support from their family because they don't know how to deal with the illness" (Gwebile, 17 April 2014, pers comm). Lack of family support may not be intentional, but rather a result of stigmatization and misunderstanding surrounding cervical cancer.

VI. Challenges in the Context of the HIV Epidemic

While these barriers, and others, stand in the way of successful screening for South African women, they are particularly problematic for the HIV-positive population. In a nation so prominently affected by the epidemic, this cannot be ignored.

Research has shown that HIV positive women are more at risk of developing cervical cancer in several regards. One "study from Durban showed that HIV infection may cause HPV infection to progress quickly from pre-invasive disease to frank invasion", causing the HIV-positive population tested to develop cervical cancer "15 years earlier than the HIV-negative control group" (Botha, 2009, p.446). One health provider even says that her clinic has "had young women with significant cervical disease at age 19 or 20" (Firnahber, 17 March 2014, pers comm). Another study found that "HIV-positive women are almost five times more likely to present with dysplasia", or pre-cancerous abnormalities (Sibiya, 2012, p.44). Therefore, "cervical cancer is regarded as an important AIDS-related disease and since 1993 has been considered as an AIDS-defining illness in women with HIV virus" (Sibiya, 2012, p.44). The risk of HIV-positive women has been heightened with the recent widespread use and availability of antiretroviral treatments. "With ARVs they can now live much longer which gives them all the more reason to get smears" (Firnhaber, 17 March 2014, pers comm).

Given their greater risk and the existence of life-extending drugs, it is undeniable that this population is particularly vulnerable and in need of a successful screening program. However, effective policy implementation is lacking. One physician at an HIV clinic says, "about 70% of women we see have heard of Pap smears, but many may not know that they are at higher risk for cervical cancer" (Firnhaber, 17 March 2014, pers comm). As a result, numerous health providers in treatment facilities acknowledge that the biggest proportion of diagnosed patients they see are also HIV-positive. "Almost all patients in the clinic are HIV positive", says Professor Denny of the Groote Schuur colposcopy clinic, "in fact, it's rare to see one who isn't" (14 April 2014, pers comm). Similarly, "2/3 to ¾ of patients are HIV positive" in the Tygerberg Hospital oncology outpatient clinic (Paris, 8 April 2014, pers comm). At one CANSA Care Home, "many of the cervical cancer patients are between 35 and 55 years old", and "a lot of the younger patients are HIV positive" (Hill, 10 April 2014, pers comm).

It is undeniable that "HIV-infected women have been seriously disadvantaged by the lack of a formally implemented screening strategy" (Snyman, 2013 p.3). Successfully carrying out a cervical cancer prevention programme in South Africa would entail giving special attention to the significant population that is HIV-positive, and thus most desperately in need of thorough support, education, and screening.

Part Two: Looking Ahead

I. Points of Success

While issues with access, follow-up, resources, awareness, stigma, and fear remain significant challenges to the success of national cervical cancer screening policy in practice, there are also several points of success. The tireless work of health providers, NGOs, advocates, and individuals to improve prevention is worth noting.

In recognition of problems with access and follow-up, health providers battle tirelessly to encourage initial appointments and returns among their patients. Professor Denny dedicates much of her time and resources at the Groote Schuur colposcopy clinic to supporting an extensive system of staff that encourage follow-up through phone calls and home visits. The result is promising. "At my clinic, we're running at about a 20% default rate", she says, "Most clinics are running at about 60%" (Denny, 14 April 2014, pers comm). In addition, access and follow-up is improved by encouraging one-time visits. Most patients "are struggling financially, which is why we try to schedule their appointments on the same day" (Gwebile, 17 April 2014, pers comm). One-time visits may be particularly successful in the case of HIV-positive patients. One NGO, Right to Care, provides smears directly at the HIV clinic, rather than referring patients to another hospital, where they are much less likely to return to be screened (Firnhaber, 17 March 2014, pers comm). Other providers agree that "it is a good idea to do Pap smears right there and then at the HIV clinics", as women will often not go when referred to another building (Briton, 9 April 2014, pers comm). Another nursing sister says, "if a woman tests positively for HIV, a smear appointment is immediately made", though she takes the opposite approach of same-day smears by choosing to do it in a second appointment "to not traumatize them too much" after one already tough diagnosis (Duckitt, 10 April 2014, pers comm).

Part of the solution to improving access and awareness may also include bringing services to patients. The experiences of some patients are testament to the success of this approach. Of her first Pap smear at the local clinic, Marie* says, "I did not request it-the doctor offered" (8 April 2014, pers comm). Ndu* says that she had her first Pap smear 5 years ago, at her workplace. Nursing sisters from the clinic make weekly visits to the factory where she is employed and leave posters advertising monthly screenings by a doctor. Interested women can

write their names down on the list for an appointment. “The sister came and told us to get the Pap smear”, Ndu* says, providing a rare example of preventative services made readily available (9 March 2014, pers comm).

One former reproductive health promoter says that her team phoned patients, organized community talks and open screening days at community health clinics, and even visited patients door-to-door to increase access and follow-up (Hill, 10 April 2014, pers comm). Right to Care uses 3 mobile vans that travel to rural South African villages to improve access. The vans have so far had successful turn-outs and are readily gaining notoriety, seeing anywhere from 75-300 patients a month for free Pap smears, depending on the region (Firnhaber, 17 March 2014, pers comm). CANSA also uses mobile vans that travel monthly to rural regions to promote preventative services (Duckitt, 2 April 2014, pers comm). Additionally, social workers tasked with helping patients apply for disability grants and cope with their diagnoses bring their services beyond the hospital, facilitating “community support groups in townships, because many women cannot afford to come often” to major hospitals (Gwebile, 17 April 2014, pers comm). They also bring food parcels to women during the 2-3 months in which they are waiting for their government grants to arrive (Gwebile, 17 April 2014, pers comm). In one rural KwaZulu-Natal clinic, nursing sisters work to promote access and follow-up by advertising through health education conducted on-site (Ama*, 10 March 2014, pers comm). In addition to conducting health education sessions and screenings in “work places, church groups, homes for the aged, and schools”, CANSA advertises by putting “notices in local newspapers delivered free of charge in poor communities” (Mahali, 7 April 2014, pers comm). A staffer acknowledges that this work is not easy and is an ongoing project, saying, “we work hard to get the message out there in communities and to get people aware of early prevention” (Mahali, 7 April 2014, pers

comm).

In some cases, providers have found that combatting a resource shortage and improving awareness among vulnerable populations is best done with local resources. While "there were no Pap smears in Khayelitsha" initially, the township cervical cancer screening project team "trained local staff to give them", resulting in the widespread use of local clinic smear even after the official project's termination (Briton, 9 April 2014, pers comm). Beyond providing medical expertise, locals are also used to promote awareness. CANSA employs peer educators from within the community, "as opposed to someone with a professional degree" (Hill, 10 April 2014, pers comm). This is done because "it's easier for women to identify with someone in their own community" (Hill, 10 April 2014, pers comm). Similarly, other initiatives have recognized the value in understanding and including the community. "You must get buy-in from the community because a lot of uneducated people there think that they're guinea pigs for a research project", says the manager of a township cervical cancer screening project " (Briton, 9 April 2014, pers comm). They did so by training local staff, advertising in popular community venues, reimbursing patients for their time, and guaranteeing follow-up services where needed (Briton, 9 April 2014, pers comm).

Sometimes, raising awareness and altering mainstream misconceptions is as simple as having a conversation with a woman, or explaining in plain English what successful prevention entails. One provider prefers to explain to women before she examines them, saying, "we tell them it's the opening of the womb, or the doorway to the womb, where a virus called HPV can cause cells to change and become cancerous" (Firnhaber, 17 March 2014, pers comm). Similarly, another professional explains "when we did the screening, we also educated them about how a Pap smear works and why you need them" (Hill, 10 April 2014, pers comm). One-on-one,

explanatory meetings like these are valuable for confused and scared women dealing with a sensitive, private matter. “The pamphlets mostly just pile up”, a nurse acknowledges, “it is much better to sit down with someone and have a conversation” (Duckitt, 2 April 2014, pers comm). Ndu* offers evidence of the value in explanations, saying the nursing sister who visited her workplace taught them “it is very good to get the Pap smear because if you catch it early it’s very easy to help but so hard when it’s all over the body” (9 March 2014, pers comm). Women are not the only ones targeted for education and awareness: “we spoke to the males also. They need to let their women be aware. We encouraged them to be together for the talks” (Hill, 10 April 2014, pers comm).

A focus on improving awareness and discussion may help to eliminate fear and shame. Recently, “younger women are more aware and more likely to open up and speak about ‘down there’” (Briton, 9 April 2014, pers comm). This may be improving simultaneously with growing awareness about HIV, and the fact that “bringing HIV out into the open is helping people to feel more comfortable talking about gynecological issues” (Briton, 9 April 2014, pers comm). Still, “it’s important to encourage people that it’s normal-every woman has a vagina”, and to emphasize the true facts about prevention (Briton, 9 April 2014, pers comm). If all South African women are to be reached equally by the proposed screening policy, nationwide discussion must be started to eliminate the common fear, shame, and stigma surrounding cervical cancer.

Though health providers and advocates are often the first to admit that there is still much to be done to increase screening among South African women, these gestures, and many others, indicate that proactive steps are being taken towards prevention. Though the challenges may be daunting, such testimonies are evidence of the possibilities for future success.

II. The Promise of the HPV Vaccine

Amidst discussion about the best ways to improve cervical cancer screening coverage, one topic continually surfaces. In many Western nations, an alternative to screening is prevention via a relatively new and effective HPV vaccine for young girls. If a population-wide vaccination program is successfully implemented, it is hypothesized that "70% of cervical cancer cases in the current generation of South African girls can be prevented"(Hoffman et. al, 2002, p.573). South Africa's Health Minister Aaron Motsoaledi is taking steps to make this promising possibility a reality. On March 12th 2014, he launched the first African program "to provide grade four girls in all government schools" with the vaccine Cervarix at the state's cost (Green, 2014, p.1). The age group was chosen with the intent of reaching girls who are not yet sexually active, as the "vaccines are most effective if administered to individuals who have not previously been exposed to HPV" (Snyman, 2013, p.3). The dose, administered by 3,000 trained professionals to girls with parental consent in 17,000 nationwide schools, will be given in two rounds (Duckitt, 10 April 2014, pers comm). If all goes as planned, the second dose is scheduled to be administered in October 2014.

The option is hotly debated, part of the reason being that it could "amount to a license to have sex and undermine the abstinence movement" (Bello, 2011, p.27). Some worry that it could downplay "the many remaining physical, psychological and spiritual health risks to young people of underage sex" (Stammers, 2006, p.7). At CANSA, staff have seen evidence of these concerns among parents, who are "afraid that it will encourage their daughters to become sexually active earlier" (Duckitt, 2 April 2014, pers comm). The toll-free information line in the resource center has also received "a few concerns from parents who heard stories elsewhere",

although staff quell these worries by telling callers that "it's an ordinary vaccine, just like the measles" (Mahali, 7 April 2014, pers comm).

Indeed, many discount such concerns and instead laud the potential of the vaccine, insisting that it could drastically change the face of cervical cancer prevention in South Africa for the better. As one provider insists, "HPV vaccines offer a unique opportunity to change the cervical cancer scene in South Africa, where secondary prevention strategies have had only limited success" (Botha, 2009, p.447). Besides the direct impacts of the vaccine, there is potential for secondary benefits, too, if "vaccination of schoolgirls could also provide an opportunity to educate and screen adult female family members" (Snyman, 2013, p.3).

Undeniably, there are still many unanswered questions surrounding the vaccine, and measures that must be taken if it is to reach its hypothesized potential. "Competition for scarce resources" from "disease such as malaria, polio, diphtheria and tetanus constitute 'unfinished business' and remain considerably important", which may prevent total acceptance or long-term use of the HPV vaccine in South Africa (Bello, 2011, p.27). In addition, acceptance requires "education of parents, care givers, religious leaders and policy makers…it will be necessary to clearly define what the vaccine protects against and what the vaccine cannot be expected to achieve at this time" (Bello, 2011, p.27). "Endorsement by faith leaders or community elders" who are often most skeptical and well-respected may help to improve education as well (Fiander, 2011, p.129). Healthcare workers must also be educated about the "need for continued screening despite the vaccine…and the details of vaccine efficacy and its side effects" (Bello, 2011, p.27). Finally, "multisectoral collaboration (including communities, health professionals, NGOs, and faith-based organizations)" will ultimately be the key to eliminating misconceptions and successfully reaching South Africa's most vulnerable females (Bello, 2011, p.28).

Though "access to human papillomavirus vaccines will be a major determinant of cervical cancer rates in developing countries…access to quality screening, diagnostic and care systems are also vital" and must continue to be studied closely for improvement (Day & Gray, 2013, p.47). "Neither vaccine has been proven to prevent cervical cancer" entirely, which is why additional prevention measures are still crucial (Stammers, 2006, p.7). The "HPV vaccine is good for primary prevention", recognizes one health provider, "but we still need to continue screening" (Firnhaber, 17 March 2014, pers comm). Some look unfavorably on this, pointing out that "the vaccine is therefore going to be an additional expense to such screening rather than a substitute" (Stammers, 2006, p.7). However, it may also be argued that massive expenses will be saved in treatment costs if the vaccine is successfully implemented nationwide, thus making it a strategy that is smart and cost-effective in the long-term.

III. Future Suggestions

With the incidence of cervical cancer among vulnerable populations so high despite the existence of a fifteen-year old nationwide screening policy, there is much discussion about how to improve the situation. Future strategies may combine past methods of success, as well as new suggestions for change.

One consensus is that "education is absolutely key", among both providers and the general population (Briton, 9 April 2014, pers comm). In order to improve access in rural areas and townships, as well as optimize local resources, "it is so important to teach nursing sisters to become colposcopists" (Briton, 9 April 2014, pers comm). As for patients, it is crucial to "increase awareness and health-seeking behavior among high-risk women (especially those aged 30-50 years)" (Anorlu, 2008, p.46). It is suggested that the best way to do this is through the development of relationships and meaningful conversations. "Speaking to them one-on-one is the

best way", according to one community health mobilizer (Hill, 10 April 2014, pers comm). "Treating them as humans, with respect and dignity, will give really great results", says another, who observed that patients who were previously afraid of being screened came back for social visits to the clinic after developing relationships of trust with the staff (Briton, 9 April 2014, pers comm). Others suggest that making use of "social networks and the influence of significant others" may "increase a woman's likelihood to obtain screening" (Mosavel, 2009, p.127). Therefore, future initiatives may place more emphasis on targeting males and their important role in the reproductive health of their counterparts. Also, "educating women while they are young and likely to be receptive to information" is another suggested strategy to ensure a lifelong habit of prevention (Szarewski, 1994, p.156).

Perhaps, awareness and the creation of discussion surrounding cervical cancer will be improved by integrating "cervical cancer screening programs within existing sexual and reproductive health services"(Phillips, 2013). By reaching out beyond cancer screening alone, programs may "appeal to a different audience than efforts aimed at addressing women's general health", and "more women are likely to respond and benefit" (Mosavel, 2009, p.127).

There is also discussion of changing the policy to more accurately reflect the modern needs of South Africa's women. In a broad sense, stakeholders are quick to point out aspects that are missing from the original policy. "The needs of vulnerable high-risk groups, such as women with HIV/AIDS" must be addressed, for one (Phillips, 2013). Also, "resources are required to deliver prevention programs, which need to be both sustainable and of high quality. Programs require evaluation to demonstrate what does and does not work, to allow for improvement and development" (Fiander, 2011, p.130).

More specifically, some providers suggest changing existing guidelines, including the minimum age at which the first of three free Pap smears is offered. “It would be better, especially in light of women becoming sexually active younger and the HIV epidemic”, to consider offering government-funded Pap smears before age 30, potentially even “as soon as women become sexually active” (Duckitt, 10 April 2014, pers comm). Policy amendments may also consider offering more frequent Pap smears, possibly “at least once every 5 years”, though “the private doctors will often recommend at least once a year” (Duckitt, 10 April 2014, pers comm).

However, others negate these suggestions in recognition of the fact that scarce resources and accessibility challenges may complicate the matter. “The ‘single visit approach’ for prevention of cervical cancer, using low-cost and low-technology screening methods” is one preferred alternative to multiple lifetime Pap smears (Anorlu, 2008, p. 46). Specifically, “fast, innovative screening tests such as visual inspection with acetic acid (VIA)…need further investigation (Ramkisson et. al, 2010, p.39). These single-visit approaches would entail “screening all women aged 35–50 years at least once, before expanding the services and providing repeated screening”. In order to be successful, the method would have to be “a screening test with high sensitivity (since women have less frequent opportunities for repeated screening)”(Sankaranarayanana, 2001, p.960).

Unfortunately, the root of the problem may go much deeper than resource shortages, accessibility challenges, and limited knowledge. First, “poverty in sub-Saharan Africa needs to be addressed seriously” (Anorlu, 2008, p.46). Many of South Africa’s women find themselves in situations of vulnerability due to the constraints imposed by their low socioeconomic status. This creates a vicious cycle of disease and poverty that may only be reversed if dealt with beyond

short-term solutions. Institutional change is also paramount. Though a policy does exist, successful implementation of it would require "greater political commitment" (Sibiya, 2012, p.47). The government must accept cervical cancer "as an important public health problem alongside competing healthcare priorities" if it is to see true change (Fiander, 2011, p.130). If political institutions endorse and promote cervical cancer as a pressing health issue, it may help to reduce stigma and start the conversations that need to be had. This can inspire "the empowerment of women to expect and indeed demand proper screening programmes to be in place", and "lead to increased acceptance of screening requirements by women" (Botha, 2010, p.24).

CONCLUSIONS

"Prevention of cervical cancer in Africa seems daunting, even overwhelming, but the scale of the problem means that we cannot ignore it" (Fiander, 2011, p.122). In South Africa, particularly, cervical cancer remains a dire problem though a nationwide screening policy was introduced in 2000. It is the number one cancer killer of poor, black women, and is increasingly claiming the lives of young HIV-positive women despite the fact that it is a preventable disease. Why is this so? It is a combination of intersecting physical, socioeconomic and cultural factors, unique in different contexts and deeply intertwined, that make certain female populations so much more vulnerable to the disease. Yet this does not have to be the case. Experts, advocates, health providers, individuals, and organizations across the country are working tirelessly to eradicate these barriers and prevent the disease. Undeniably, much work remains to be done, and improvements must be made in access, awareness, cultural acceptance, and resource provision, among other things. Many questions, frustrations, and challenges still stand in the way of

successful screening for those who need it most. Yet with collaboration across sectors, institutional change, and the ongoing exploration of new suggestions and solutions, these challenges may be addressed to turn the nationwide screening policy into a reality and create sustainable change.

I. Limitations & Sources of Bias

While the set-up and design of the study did have its advantages, it is undeniable that there are limitations and sources of bias. Firstly, rather than randomly selecting participants to be representative of a population, I chose to interview women who I already knew. This may have led to participants feeling pressure to talk to me or answer in a certain way based on our previously established relationships. In addition, a lack of time and resources limited me to a small sample size that can offer only a glimpse of the issue, rather than a well-rounded picture that more sophisticated studies are able to provide. However, my hope is that such a small, in-depth sample, has, in some senses, a unique value of its own.

The interviews with health providers and experts at various locations may also have been exposed to bias. The participants are single individuals at very specific locations who undeniably have opinions and experiences that vary from others in the field. In addition, their conditions of employment or the interview environment may have led them to answer in a certain way, while conversely my status as a white, foreign visitor may have inspired pressure to participate, though I assured each individual of their right to refuse.

Additional individuals were selected for participation based on snowball sampling and outside research. This carries the risk of limiting the study to a small circle of experts with narrow perceptions and similar experiences, who can only understand the realities of their subjects to a certain extent. It is also important to note that many health provider participants

were higher-income white individuals whose reality is undeniably different than the women they treat. Therefore, they undeniably have limited perspectives of the experience of cervical cancer for South African women.

Finally, information gathered in the participant observation period is limited to a small group of staff members and a single organization. Staff information may have been influenced by pressure from the employing organization, and only reflects the stances and customs of one association among hundreds. In addition, my personal observations and experiences were doubtless shaped by a limited access to information and inexperience in the medical field, as well as my status as a middle-class, white American student.

While I have done my best to avoid such biases and acknowledge the limitations at hand, it is important to note that they do exist and may have a tangible effect on the information produced in this study.

II. Recommendations for Further Study

Though this study aims to investigate the barriers to successful cervical cancer screening in South Africa, it only covers a few small areas and organizations. The information gathered was largely collected from contacts at CANSA and associated healthcare providers in urban Cape Town, though some data from urban and rural regions of KwaZulu-Natal is also referenced. Therefore, further studies might investigate the status of this issue in other regions of South Africa. It might be particularly relevant to look at rural, poor regions, where rates of cervical cancer have been shown to be highest.

Further studies may also focus in more detail on the status of cervical cancer prevention with regards to the HIV epidemic. In the majority of settings where data was collected, HIV-positive women were present and referenced continuously by health providers. The status of the

epidemic in South Africa and its relationship to cervical cancer merits further investigation of screening for this particular population, and the ways in which current policy and procedures might be adjusted to more appropriately address needs.

Finally, it may also be interesting to investigate the HPV vaccine program in more detail. The initiative, recently implemented for the first time in the public health system of an African nation, is currently very relevant. Policies, discussion, and results of the project are unstudied in detail as of yet. This will likely remain a topic of importance for some time to come, and it is undoubtedly worthy of further investigation, as it has the potential to alter future cervical cancer screening guidelines and programs.

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APPENDICES

Appendix A: Glossary of Terms

CANSA: The Cancer Association of South Africa, a non-governmental organization dedicated to fighting cancer in South Africa through education, research, and support.

NGO: non-governmental organization.

HIV: Human Immunodeficiency Virus, a sexually transmitted infection that weakens the immune system. HIV-positive women are more at risk of developing cervical cancer, both at a younger age and a greater severity.

Cervix: the narrow neck of tissue connecting the vagina and the uterus.

Papanicolaou (Pap) smear: a method of cervical screening in which a speculum is used to open the vagina and allow for the collection of cells from the cervix. The cells are then examined in a laboratory to determine if any abnormalities exist that may develop into cancer.

Colposcopy: A diagnostic procedure that uses light and magnification to examine cervical abnormalities and detect precancerous lesions for treatment.

HPV: Human papillomavirus, an infection that is primarily sexually transmitted. Several strains of HPV infection are responsible for nearly all cases of cervical cancer.

HPV DNA Testing: A test to detect the presence of HPV, sometimes done in conjunction with a Pap smear.

VIA: Visual inspection with acetic acid, a screening method where acetic acid is applied to the cervix and then examined with the naked eye. Precancerous lesions may be indicated by a

change in color to white. This is often suggested as an attractive alternative to Pap smears for its lesser requirements in cost, resources, and medical visits.

Cervarix: a vaccine designed to prevent infection from HPV 16 and 18, two common precursors of cervical cancer. The vaccine, approved for use in females aged 9 to 25 years, is administered in two doses. In March 2014, it was made available for grade 4 girls in South African public schools for the first time.

Dysplasia: an abnormal change in cells or tissues.

Right to Care: An NGO that provides, among other services, cervical cancer screening for HIV-positive patients in South Africa.

Khayelitsha: A Cape Town township where Professors Briton and Denny conducted a cervical cancer screening project from 1996-2012.

Appendix B: Statement of Ethics Form

SIT Study Abroad
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Statement of Ethics

(adapted from the American Anthropological Association)

In the course of field study, complex relationships, misunderstandings, conflicts, and the need to make choices among apparently incompatible values are constantly generated. The fundamental responsibility of students is to anticipate such difficulties to the best of their ability and to resolve them in ways that are compatible with the principles stated here. If a student feels such resolution is impossible, or is unsure how to proceed, s/he should consult as immediately as possible with the Academic Director (AD) and/or Independent Study Project (ISP) Advisor and discontinue the field study until some resolution has been achieved. Failure to consult in cases which, in the opinion of the AD and ISP Advisor, could clearly have been anticipated, can result in disciplinary action as delineated in the "failure to comply" section of this document.

Students must respect, protect, and promote the rights and the welfare of all those affected by their work. The following general principles and guidelines are fundamental to ethical field study:

I. Responsibility to people whose lives and cultures are studied

Students' first responsibility is to those whose lives and cultures they study. Should conflicts of interest arise, the interests of these people take precedence over other considerations, including the success of the Independent Study Project (ISP) itself. Students must do everything in their power to protect the dignity and privacy of the people with whom they conduct field study.

The rights, interests, safety, and sensitivities of those who entrust information to students must be safeguarded. The right of those providing information to students either to remain anonymous or to receive recognition is to be respected and defended. It is the responsibility of students to make every effort to determine the preferences of those providing information and to comply with their wishes. It should be made clear to anyone providing information that despite the students' best intentions and efforts, anonymity may be compromised or recognition fail to materialize. Students should not reveal the identity of groups or persons whose anonymity is protected through the use of pseudonyms.

Students must be candid from the outset in the communities where they work that they are students. The aims of their Independent Study Projects should be clearly communicated to those among whom they work.

Students must acknowledge the help and services they receive. They must recognize their obligation to reciprocate in appropriate ways.

To the best of their ability, students have an obligation to assess both the positive and negative consequences of their field study. They should inform individuals and groups likely to be affected of any possible consequences relevant to them that they anticipate.

Students must take into account and, where relevant and to the best of their ability, make explicit the extent to which their own personal and cultural values affect their field study.

Students must not represent as their own work, either in speaking or writing, materials or ideas directly taken from other sources. They must give full credit in speaking or writing to all those who have contributed to their work.

II. Responsibilities to Hosts

Students should be honest and candid in all dealings with their own institutions and with host institutions. They should ascertain that they will not be required to compromise either their responsibilities or ethics as a condition of permission to engage in field study. They will return a copy of their study to the institution sponsoring them and to the community that hosted them at the discretion of the institution(s) and/or community involved.

III. Failure to comply

When SIT Study Abroad determines that a student has violated SIT's statement of ethics, the student will be subject to disciplinary action, up to and including dismissal from the program.

I, Amanda Cameci, have read the above Statement of Ethics and agree to make every effort to comply with its provisions.

Date: 3/27/14

Appendix C: Local Review Board Action Form

SIT Study Abroad
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Human Subjects Review
LRB/IRB ACTION FORM

Name of Student: Amanda Comeau

ISP Title: Barriers to successful cervical cancer screening in rural kwazulu-Natal, Cato Manor, and Cape Town, South Africa

Date Submitted: 3/28/14

Program: School for International Training

Type of review:

Exempt ☐
Expedited ☑
Full ☒

Institution: World Learning Inc.
IRB organization number: IORG0004408
IRB registration number: IRB00005219
Expires: 22 December 2014

LRB members (print names):
Mr. John McGladdery
Ms. Angela James
Mr. Clive Bruzas

LRB REVIEW BOARD ACTION:

____ Approved as submitted
____ Approved pending changes
____ Requires full IRB review in Vermont
____ Disapproved

LRB Chair Signature:

Date: 04/01/2014

Form below for IRB Vermont use only:

Research requiring full IRB review. ACTION TAKEN:

__ approved as submitted __ approved pending submission or revisions__ disapproved

IRB Chairperson's Signature

Date

Appendix D: Example of Consent Form for Adult Respondents

SIT Study Abroad

a program of World Learning

1. **Brief description of the purpose of this study**

The purpose of this study is to explore the current policy for cervical cancer screening and the challenges of implementing it among South African women. The study will combine input from individual women, medical professionals, experts, and academics in order to gain a well-rounded perspective of the different socio-economic, physical, and cultural barriers involved. Ultimately, the study aims to investigate how the policy may be more successfully carried out in the future for improved prevention of cervical cancer.

2. **Rights Notice**

In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.

   a. ***Privacy*** - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.
   b. ***Anonymity*** - all names in this study will be kept anonymous unless you choose otherwise.
   c. ***Confidentiality*** - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to you.

I understand that I will receive **no gift** or direct benefit for participating in the study.

I confirm that the learner has given me the address of the nearest School for International Training Study Abroad Office should I wish to go there for information. (404 Cowey Park, Cowey Rd, Durban).

I know that if I have any questions or complaints about this study that I can contact anonymously, if I wish, the Director/s of the SIT South Africa Community Health Program (Zed McGladdery 0846834982).

Participant's name printed: _____ Your signature and date: _____
Interviewer's name printed:_____ Interviewer's signature and date:_____

I can read English. (If not, but can read Zulu or Afrikaans, please supply). If participant cannot read, the onus is on the researcher to ensure that the quality of consent is nonetheless without reproach.

Appendix E: Consent to Use of ISP

SIT Study Abroad
a program of World Learning

Consent to Use of Independent Study Project (ISP)

(To be included with the electronic version of the paper and in the file of any World Learning/SIT Study Abroad archive.)

Student Name: Amanda Comai

Title of ISP: Barriers to successful Cervical Cancer screening in rural KwaZulu-Natal, Cato Manor, and Cape Town

Program and Term: Spring 2014, Durban Community Health and Social Policy

1. When you submit your ISP to your academic director, World Learning/SIT Study Abroad would like to include and archive it in the permanent library collection at the SIT Study Abroad program office in the country where you studied and/or at any World Learning office. Please indicate below whether you grant us the permission to do so.

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